

Our patients are inspiring...

“Everybody was so friendly and caring.”

Support team arrange for carers, at Squire’s Garden Centre - a location which separates them from both home and Hospice, and where they can go to share their feelings with others who are in the same boat.

Eddy has also requested to meet with one of Phyllis Tuckwell’s counsellors, which she is looking forward to. *“It can be very lonely. People around you are afraid or embarrassed to talk to you about the illness,”* she confides.

When asked how he feels about his illness, Steve is honest and direct. *“I’m not afraid of it,”* he says. *“People say I’ve got a lot of strength, but there’s no point in sitting on the negatives. So much of it is mind over matter.”*

His positive attitude is matched by those who have cared for him at the Hospice. *“They are motivational and inspirational without even realising it. **They inspire you – they make me want to do more and different things.** I can spend all day making a list of the things I can’t do,”* he adds, as Eddy listens, nodding in agreement. *“I’d rather make a list of the things I can do, and go and do them”.*

“It’s not about end of life,” he concludes. **“It’s about rest of life.”**

We are privileged to care for people like Steve and his family, at probably the most difficult time in their lives, but we can only do this with the generosity of our local community.

We have to raise over £20,000 every day in order to provide care, free of charge, to our patients and their relatives.

For further information about how to support Phyllis Tuckwell Hospice Care, contact our Fundraising team on:

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support@pth.org.uk

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Living Well

Steve’s Story

Carers sessions, counselling and coffee mornings

Phyllis Tuckwell[®]
Hospice Care
...because every day is precious

November 2017

Steve's Story



Steve was working for O2, as a National Sales and Marketing Manager, when he was diagnosed with Multiple Sclerosis (MS), 25 years ago. It was a tough blow to deal with and it was made even harder when, three months later, his wife left him.

Steve spent the next 18 months living on his own, coming to terms with both his illness and the end of his marriage. However, in his typically optimistic manner, he was determined to carry on living life to the full, and decided that he would join a dating agency. After an initial conversation, the agency sent round one of their staff members to interview Steve, with a view to matching him to potential new partners. The staff member was named Edwina, and that initial interview was all she and Steve needed to decide that they were actually the right partners for each other!

"I saved him about £500 in agency fees!" jokes Eddy, as they sit together with a cup of tea.

At first, with his wheelchair to keep him mobile, Steve was able to continue working, and spent the next 12 years travelling across the UK, working for Hitachi, O2 and BT. *"I just got on with the job"* he says, his determination showing through his cheerful smile. Twenty years after his initial diagnosis, however, Steve's illness meant that he was no longer able to work.

As his illness progressed, Steve began to suffer from pressure sores and infections, and was admitted to hospital, where he remained for nearly a whole year.

Once he had been discharged and was able to return home, Steve began to receive daily visits from the District Nurse team, and it was during one of these visits that he was first introduced to Phyllis Tuckwell Hospice Care.

"It unsettled me" he confides. *"My first thought was – am I going to die?"*

The first time Steve visited the Hospice was for a week of respite care. ***"I was just totally amazed – I was lost for words,"*** says Steve, recalling that time.

He was given his own room and had some gentle physiotherapy to keep his muscles and joints loose.

"Everybody was so friendly and caring; the people who work there really want to work there," Eddy confirms, as Steve adds ***"nothing was too much trouble. It gave me a lot of confidence and courage,"*** he recalls. ***"A whole new lease of life. I wasn't a write-off."***

"They have time to talk and to listen," says Eddy. ***"Honesty is one of the biggest things about it – if you ask them a question they will tell you the truth."***

After his week of respite care Steve went back home, but since then has started attending Day Hospice, where he can come for day-long sessions once a week, for six-weeks at a time. As well as the social aspect of getting out of the house and meeting other people in a similar situation to him, Steve is also able to receive reflexology and massage treatments, which help with his pain and discomfort.

The time which Steve spends at the Day Hospice is also beneficial to Eddy, as it gives her a break from being a full-time carer, allowing her to have some time to herself. Eddy doesn't even have to drive

Steve there, as Phyllis Tuckwell arranges for him to be picked up and taken home each time. ***"Being able to give Eddy a break is really important to me,"*** says Steve.

At first Steve found the sessions, which are usually all day, too fatiguing - so Phyllis Tuckwell staff arranged for him to attend for half a day at a time, although, if he doesn't feel too tired, Steve sometimes manages to stay for longer.

Since his week of respite care, Steve has spent several more weeks at the Hospice over the last year. *"Things aren't getting better,"* he concedes, *"but you learn to manage them. Eddy is my strength and my whole life."*

"When we first met," Eddy adds, *"Steve knew very little about MS. We were both working in the dark."* After meeting Steve, Eddy was mindful that she wanted to understand the illness before she committed to their relationship, and spent a lot of time reading books and articles on the illness. *"But it doesn't really prepare you for when it gets worse,"* she says.

Phyllis Tuckwell has also helped Eddy - as Steve's wife and full-time carer - through counselling and support groups. Eddy was invited to attend Phyllis Tuckwell's 'What About U?' sessions, a series of weekly therapeutic sessions which run over eight weeks and are held twice yearly. Through these sessions, Eddy has met other carers in a similar situation to her, and has made one particular friend whom she still keeps in touch with, even though her sessions have now finished. She also plans to try one of the monthly coffee mornings which Phyllis Tuckwell's Patient and Family

